Pakistan Journal of Clinical Psychology, 2025 24, 1, 43-57 | PJCP

PSYCHOLOGICAL DISTRESS AND QUALITY OF LIFE AMONG PEOPLE WITH CONGENITAL AND ACQUIRED PHYSICALLY DISABILITIES

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ABSTRACT

Objectives: *The aim of the current study was to investigate the difference in the levels of psychological distress and quality of life among people with congenital and acquired physical disabilities.*
Design of the Study: *Cross-sectional research design.*
Place and Duration of Study: *Data was collected from September 2023 to January 2024, at the University of Peshawar.*
Sample and Method: *The sample consisted of individuals with physical disabilities (N=80) with the age range between 18-65 years (X=35.11, SD= 14.49) were selected through purposive sampling technique from the OPDs of various health care setups dealing with physical disabilities. DASS-21 and WHO Quality of Life Scale were used as study tools.*
Results and Conclusion: *The finding indicated that people with congenital physical impairment experienced lower levels of stress and depression as well as higher quality of life than those who acquired them; however, no significant difference was found in the score of anxiety of both groups. The findings reveals the psychological challenges encountered by people having physical limitations, and the need for specialized mental-health treatments and rehabilitation, as well as role of social support to improve coping mechanisms and overall quality of life.*

Keywords: *Congenital and Acquired physical disabilities; Psychological distress; Quality of life; Depression; Anxiety; Stress.*

INTRODUCTION

Health has been defined as individual's general physical, mental, and social well-being, not just the absence of illness or ailment (WHO, 1980). The idea of quality of life as a factor relating to health has recently been incorporated. The impairments comes under the physical aspects of health, disability defined as the loss of functional capacity due to an impaired organ, whereas the social and cultural effects of an impairment or disability are called a handicap (WHO, 1980; WHOQOL Group, 1993). Barbotte et al. (2001) found that disability affects the psychological condition, independence level, social bond, relationship with family, and friend as well as the physical health of effected person. Disability vastly create impact largely on every level such as personal, interpersonal, familial, and societal, and these concerns make it more prominent mainly in medicine and psychology fields. People having disabilities remain on the lowest edge of society (Hosain et al., 2002). The International Year of Disabled Persons (1981) highlighted extensive interest in disability across the world. As per the estimation of UNICEF, four among five people with disability live in developing countries, where insufficient level of welfare as well as health-care facilities, and overall development level further contribute to the low quality-of-life for those having disability. The report on disability by WHO (1980) states that worldwide, there is heap, over 15% of the entire population live with disabilities, the number is increasingly day by day due to upsurge in non-fatal injuries such as traffic accidents, catastrophes, and non-communicable illnesses. All these can result in chronic health conditions as well as impairments and the effected people must live with for years (Fellinghauer et al., 2012).

Various International Classification of Functioning, Disability and Health components, have defined disability as having difficulty in functioning i.e., activities and participation limitations, and impairment in bodily structures and associated functions. According to Ustan et al. (2003), environmental factors as well as personal factors also create impact on all these elements and on their interaction with each other.

There are limited findings on the link of earlier onset and greater response to impairment. Li and Moore (1998) found that, individuals with congenital disabilities showed more openness to accept of their disability than those having acquired type. They did not have premorbid identity; therefore, they may perceive the disability as an integral part of them and report being unaware of themselves without it. Conversely, people having acquired type of disabilities describe a deep sense of identity loss (Bogart, 2014; Smart, 2008). A number of

studies revealed that individual having disabilities are expected to reduced participation in day-to-day activities, experience health problems both physical and mental, and low self-esteem, and engaged in risky behavior (Okoro et al., 2009; Reichard et al., 2011). It was further revealed by the studies that people with disabilities are more prone to experience significant psychological distress (SPD) than those without disabilities (Okoro & Dhingra, 2014). The World Health Survey from 2002 to 2004 estimated 13.4% of Pakistani population are facing disabilities. According to Kanwal and Mustafa (2016), disability is a general concept include obstructions, mobility limitations, participation limitations, and the effected people struggle in physical duties because of having issue(s) with their body shape and structure.

Viemero (1991) has stated that the quality of life of the people with severe physical disabilities has greatly enhanced over the last two decades, owing mostly to well-structured intervention programs targeting psychological and social adjustment processes, in addition to physical treatment. However, regardless of the duration of that state, some of the people with disabilities cannot adjust adequately in life. Discussion have also been made on those who adjust well irrespective of the level of handicap (Viemero & Krause, 1998).

According to the World Health Organization, quality of life may be defined as perception of people about themselves in terms of their aims, values, hopes, and uncertainties in the context of their culture and value systems. The concept gets impacted by individual's health status, independence level, societal connectedness, beliefs and association with other aspects of their environs (Okoye et al., 2022). Individuals with disabilities are considered as the most sidelined population in society that continually face hindrances while trying to exercise their rights. In Pakistan, PWD are often set apart from their healthy counterparts and are not allowable to take active part in society along with those without disabilities (Hussain et al., 2022). It has been further revealed that disability is linked with low self-esteem, inadequacies, societal seclusion, and indignity, all in turn lead to low quality of life (Kanwal & Mustafa, 2016). Rehabilitation has been found crucial to improve quality of life of these people along with the functional restoration (Ullah et al., 2023).

Research findings showed that physical handicap adversely affect the number of dimensions of the QoL, especially psychological domain. People with physical disabilities have less knowledge about the resources they may have as per the Persons with Disability Act. Ramadass et al. (2018) also revealed the

association between the disability and sociodemographic features. Study also revealed the greater QoL among women and the elderly with physical disabilities (Ramadass et al., 2018).

Study conducted by Kamali et al. (2013) list down the factors that affect the QoL of people with physical disability, that include physical convenience, social support, opportunities to get hired, health related services, edification and training, as well as stigma. People having physical handicaps are prone to show depressive symptoms, pessimism, passivity, as well as aggression than their able-bodied counterparts. Alexithymia, and somatization also prevail commonly among males. They also have inadequate social amalgamation and are living in social isolation (Viemero & Krause, 1998). Sheriff (2003) revealed that children with acquired type of disabilities tend to experience lower QoL as compare to those having congenital type of physical disabilities due to incapability to perform the tasks they once were able to do, and the realization of the acquired limitations and associated challenges further lead to social, mental, and even physical issues. Literature review highlighted the dearth of knowledge about the psychological distress as well as quality of life of people with physical disabilities. To address this gap, current research has been aimed to explore the level of psychological distress, and quality of life of people with congenital, and acquired physical disabilities. Following hypotheses were framed

- There would be significant difference in the level of psychological distress (i.e., Depression, Anxiety, Stress) in people with congenital and acquired physical disabilities.

- There would be significant difference in the level of quality of life in people with congenital and acquired physical disabilities.

METHOD

Participants

The sample comprised of 80 people (40 with congenital physical disability, 40 with acquired physical disability), both males and females. Purposive sampling was employed, and the data was collected from Paraplegic Center Peshawar and Pakistan Institute of Prosthetic and Orthotic (PIPOS), Peshawar, Khyber Pakhtunkhwa-Pakistan. The following criteria was developed to select the study sample to control the extraneous variables.

Inclusion criteria

Individuals with diagnoses of congenital physical disabilities (e.g., muscular dystrophy, congenital limb deficiencies, cerebral palsy, spina bifida) as well as acquired physical disabilities (e.g., Leg Length Discrepancy, Trans-tibial Amputation, orthopedic issues, stroke related disabilities) for a minimum of 1 year were part of study. Additionally, the age range of the participants must be between 18-65 years.

Exclusion criteria

Individuals with recently acquired physical disabilities (i.e., less than 1 year), individuals with intellectual disabilities or neurodevelopmental disorders were excluded from the study. Furthermore, people under 18 or over 65 years of age, and those declined to participate, were not included in the study.

Measures

Demographics Information Sheet:

The demographic information sheet comprised of respondent's age, gender, number of siblings, their birth order, marital status, qualification, employment, family system, length of physical disability, and cause of it.

WHO Quality of Life Scale (WHOQOL group,1993):

The World Health Organization Quality of Life Scale (WHOQOL) has been developed that evaluates quality of life across various domains. The scale has 16 items with a 7-point Likert type scale. The instrument is scored by adding up the score on all the items, where high score indicates a greater QoL. The scale has sound internal consistency with Cronbach's alpha of 0.82–0.92.

The Depression Anxiety Stress Scale-21 (Lovibond & Lovibond, 1995)**:**

The Depression Anxiety Stress Scale-21 (DASS-21) is a self-report measure to assess the level of psychological distress. This scale consists of three subscales i.e., depression, anxiety, and stress. Each subscale has seven questions with a 4-point Likert type scale. The Cronbach's alpha values reported as for Depression = 0.81–0.94, for Anxiety = 0.73–0.92 and for Stress = 0.81–0.91 for both clinical and non-clinical population (Lovibond & Lovibond, 1995).

Procedure

The official permission was sought from the rehabilitation centers before carrying out the study. Rapport was established with the participants initially and they were assured about the confidentiality and were informed that the data would be used only for research purpose. All the questionnaires were filled out by the participants followed by the administration of informed consent form outlining the goal of the study, guidance on how to fill the forms, confidentiality, and their voluntarily participation. They were also allowed to leave the research at any moment.

Statistical Analysis

For statistical analyses descriptive statistics such as frequency distribution and percentages were calculated and to investigate the significance difference between variables undertaken, independent t- test was applied.

RESULTS

Table 1

Descriptive Statistics for the Sample of the Study

Demographics	*f*	%
Gender		
Female	38	52.5
Male	42	47.5
Age		
18-29	36	45
30-41	19	23.8
42-53	12	15
54-65	13	16.2
Types of Disability(ies)		
Leg length discrepancy	3	3.8
Transtibial Amputation	22	27.5
Transfemoral Amputation	12	15
Muscular dystrophy	9	11.1
Congenital Limb Deficiencies	13	16.3
Orthopedic Issues	18	22.5
Others	3	3.8
Causes of disability		
RTA	12	15
Fire Alarm	2	2.5
Bomb Blast	2	2.5
Diabetes	19	23.8
By Birth/Polio	40	50
Others	5	6.2
Groups		
Acquired	40	50
Congenital	40	50

N=80

Table 1 shows the Descriptive statistics of the sample characteristics.

Table 2
Difference Between Individuals with Congenital and Acquired Physical Disabilities on Psychological Distress (N = 80)

Variable	Group	*M (SD)*	*t*	*p*	Cohen's d
Depression	Congenital	2.68 (1.02)	-6.43	.006	1.44
	Acquired	3.98 (0.767)			
Anxiety	Congenital	2.25(0.44)	-13.32	.23	2.97
	Acquired	3.95 (0.68)			
Stress	Congenital	1.93(0.47)	-15.62	.005	3.50
	Acquired	4.08 (0.73)			

Note. M = Mean, SD = Standard Deviation. p-values <.05 indicate statistical significance. Table 2 shows the results of depression indicated a significant difference between the congenital group (M = 2.68, SD = 1.02) and the acquired group (M = 3.98, SD = 0.77), t(78) = -6.43, p = .006, d = 1.44. For anxiety, no significant difference was found between the congenital group (M = 2.25, SD = 0.44) and the acquired group (M = 3.95, SD = 0.68), t(78) = -13.32, p = .232, d = 2.97. For stress, a significant difference was observed between the congenital group (M = 1.93, SD = 0.47) and the acquired group (M = 4.08, SD = 0.73), t(78) = -15.62, p = .005, d = 3.50.

Table 3
Difference Between Individuals with Congenital and Acquired Physical Disabilities on Quality of Life (N = 80)

Variable	Group	*M (SD)*	*t*	*P*	Cohen's d
QOL	Congenital	2.83 (0.38)	23.64	0.006	5.3
	Acquired	1.08 (0.27)			

According to table 3, The results indicated a significant difference, t(78) = 23.64, p = .006, d = 5.30. The people with congenital physical disabilities group (M = 2.83, SD = 0.38) had a significantly higher mean score than the acquired physical disabilities group (M = 1.08, SD = 0.27).

DISCUSSION

Though, there is a great diversity in impairments, mobility disability has been found as the most prevalent type, impacting 40% of people, and causes a loss of physical functioning to various degrees. Physical limitations can result from either congenital or acquired disorders affecting the respiratory, cardiovascular, orthopedic, or neurological systems causing disorders like paralysis, cerebral palsy (CP), stroke, multiple sclerosis, muscular dystrophy, arthritis, as well as spinal cord injuries (Okoye et al., 2022). Kagan et al. (2018) found that among people having physical impairments, the duration of disability conversely related to psychological distress suggesting that people with shorter disability length are more prone to experience greater level of distress. The results of the present study have been found consistent with other findings that people with congenital physical disability have significantly low level of depression, and stress as compared to their healthy counterparts; however, insignificant difference have been found in the scores of anxiety level in both groups. Diabetic foot ulcer (DFU) and road traffic accidents (RTA) have been found as most prominent cause of acquired physically disability in the sample. Armstrong (2001) stated diabetic foot ulcers (DFU) as one of the most perilous side effects of diabetes that affects approx15% of patients and found to be one of the main reasons for non-traumatic lower limb confiscations. Almaqhawi et al. (2023) revealed that anxiety and depressive symptoms are common in people with DFUs. Prevalence of anxiety related symptoms have been found among the 40.7% of patients with DFUs, while 32.1% of the population experience depressive symptoms. Study findings (Fadia et al., 2022) also indicated depression associated to the risk of amputation and hospitalization for the individuals with DFUs. WHO estimates shows that globally on annual basis, RTAs lead to non-fatal damages for approximately 50 million individual. As, the world's 5th foremost reason of disability-adjusted life years (DALYs), RTAs majorly contribute to the burden of illness worldwide (Murray et al., 2015). RTAs also have several nonlethal effects such as functional disability, cognitive disfunction, psychological agony, and a waning in the victims' as well as the quality of life of their families. Many RTA survivors may also reportedly experience psychological problems, and the most prevalent are found anxiety, depression, and PTSD (Kovacevic et al., 2020). Higher levels of stress can be caused by a number of patient-related issues, including the burden of chronic illness, an excessive reliance on family members, and frequently co-dependence (Younas et al., 2024).

Further, the findings of the current study did not show significant difference in the scores on anxiety of both groups i.e., the congenital and acquired type disability. Uwimbabazi et al. (2023) also found that people natural physical impairments may experience stigma, prejudice, and face difficulties in receiving proper treatment and educational opportunities, that in turn have potential to exacerbate psychological issues such as anxiety. It is thought that social barriers are the cause of disadvantaged circumstances, which include the absence of certain physical, economic, or social attributes. Those with exceptional needs face societal pressure to utilize the social services that are accessible to them thus affecting their life (Bazna & Hatab, 2005). Social skills development, socialization and family support may be challenging for the adolescents having disabilities, especially those who with physical limitations of congenital in nature. The absence of a substantial difference in anxiety levels between the two groups is an intriguing discovery. It implies that both groups may feel identical degrees of uncertainty, dread, or concern, regardless of whether their disability was present at birth or developed later in life. One possible reason is that disability-related stigma, discrimination, and accessibility issues may cause persistent stresses that lead to increased anxiety in both groups (Shakespeare, 2013).

Psychological distress significantly reduce the QoL of people with congenital and/or acquired type physical disabilities. It has been found in the current research that people with congenital physical disabilities experience significantly high quality of life as compared to their counterparts. Al Syifa and Hadi (2023) found several factors for QoL of people having physical disabilities which include gender, age, degree, and length of disability. They also found that people having late onset had lower QoL (Al Syifa & Hadi, 2023). The Findings (Mushtaq & Akhouri, 2016) suggested that people with congenital impairments were more contented with their quality of life than the ones with acquired type in terms of socio-demographic and disability-related variables. Because people with congenital impairments have lived with their disease since birth, they generally acquire adaptive coping skills and a strong sense of identity in connection to their disability (Livneh, 2013). As a result, people may feel more accepting of their physical state, resulting in a more stable and happy quality of life.

Conclusion

The aim of the research was to explore the difference in the levels of psychological distress, and QoL among people with physical disability of

congenital and acquired type. Disability of any type is associated to various problems psychological in nature not only for the affected person but also cause stress and tough life for their loved ones. The situation becomes even more tough for a person previously having adequate physical health, and now reliant on others. It has been also found that people with acquired type experience more psychological distress and low quality of life than those with congenital type. Furthermore, the acquired type face greater challenges in adjusting to changes in their body and environment, loss of independence and social segregation.

Limitations and Recommendations

The study was conducted with a small size that may restrict the generalizability of the findings to a larger population. Moreover, the sample was recruited from one region of Khyber Pakhtunkhwa which limits its application to other culture and geographical situations. Other psychological factors like resilience, social support and coping strategies can be studies among these groups. This study helps in bringing the people with acquired physical disabilities in notice, also by providing awareness to the society about the difficulties and distress they face. Further, by enhancing mental health care facilities in rehabilitation units to promote mental well-being of the effected population. The small steps may have greater impact if they will be facilitated by the institutions to provide them employment opportunities in welcoming and structured work environment to maximize their potential.

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